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Off Sick Project Online Exhibition

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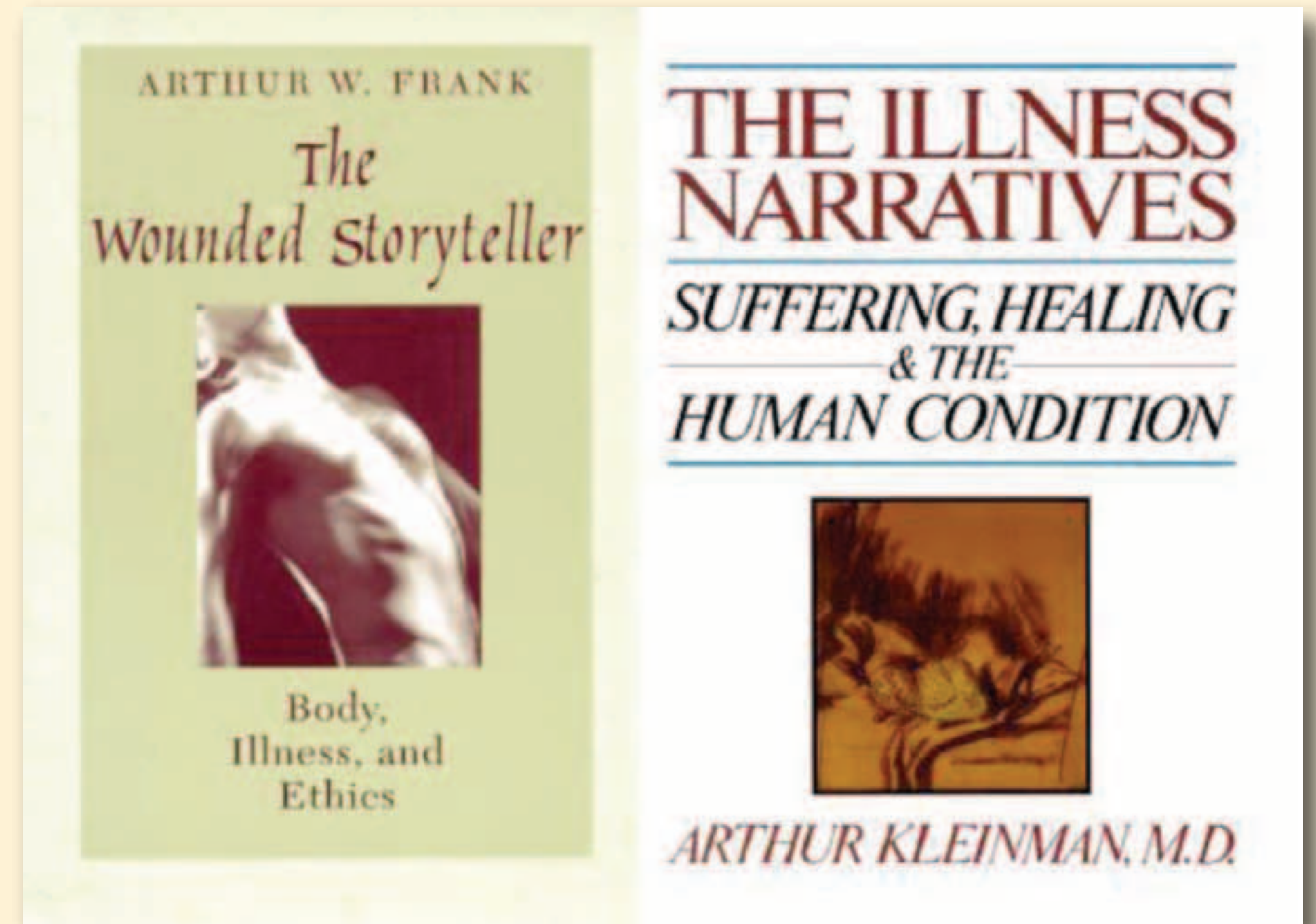
Illness *and* Narrative

Modern writers have assumed that medical institutions have disregarded patients' experiences of their illness, and have instead seen disease in de-personalised terms as a biological problem to be solved. In this perspective, it was the disease rather than the patient that took primacy.

In response, the idea of the 'illness narrative' has been used over the past few decades as a means of re-empowering patients. One consequence is that the voice of the patient has re-emerged and there is already a large and growing literature on narratives of illness.

There has been comparatively little work on the stories and experiences of family members who provide moral or practical support to people suffering from severe or long-term illness.

Just as the voices of the sufferers themselves were for a long time marginalised, so too are the voices of their families today.



“

‘One unintended outcome of the modern transformation of the medical care system is that it does just about everything to drive the practitioner’s attention away from the experience of illness.’

Arthur Kleinman (1988)

”

“

‘People telling illness stories do not simply describe their sick bodies; their bodies give their stories their particular shape and direction.’

Arthur Frank (1987)

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Strange *Places*



A corridor in High Royds Hospital, Menston, Ilkley, Yorkshire

Professionals who write about illness narratives often think of them in opposition to the medical narratives that define illness and disease from a clinical perspective. They believe that stories about illness, written by patients and others, break free from the “grand narratives” constructed by doctors and other health professionals, both now and across history.

Certainly illness narratives bring a new voice to the discussion of ill health. Yet while they might well do something different from the narratives of doctors, they still have things in common with other kinds of storytelling.

Joseph describes walking through a hospital to a particular ward:

We had to walk down a long corridor, which had a shiny buffed floor that squeaked when walked on, and you felt sure that everyone would stare at you. However, we encountered very few people along the corridors with their shiny brown hued floors, and many doors, an antiseptic smell and tubular steel trolleys left abandoned at the side of the walkway.

Sometimes the Victorian character of hospital buildings seems to have an influence on the writer. **Marie** writes: *“I followed a sign...and found a lovely old Victorian building with wood panelling and portraits on the walls. This was clearly the Chief Executive’s area and I felt I shouldn’t be there. I left...as quickly as possible to avoid what I perceived to be an inevitable confrontation if I was found there.”*

And this is how Charles Dickens describes what it felt like to walk through unfamiliar parts of London in 1859: “to feel that it would be perfectly true that I have no business here, or there, or anywhere; and yet to be perplexed by the consideration that I *am* here somehow, too, and everybody overlooked me.”

Marie describes how she feels as she tries to negotiate the unfamiliar hospital:

“I walked back through the modern part of the building which was now deserted, and out to the dark, empty walkway”

“The corridor in the accommodation block was eerily quiet. Trips to the communal toilet were quite scary. I sensed the presence of others but saw no-one.”

“The location of most facilities and offices seemed oddly placed.”

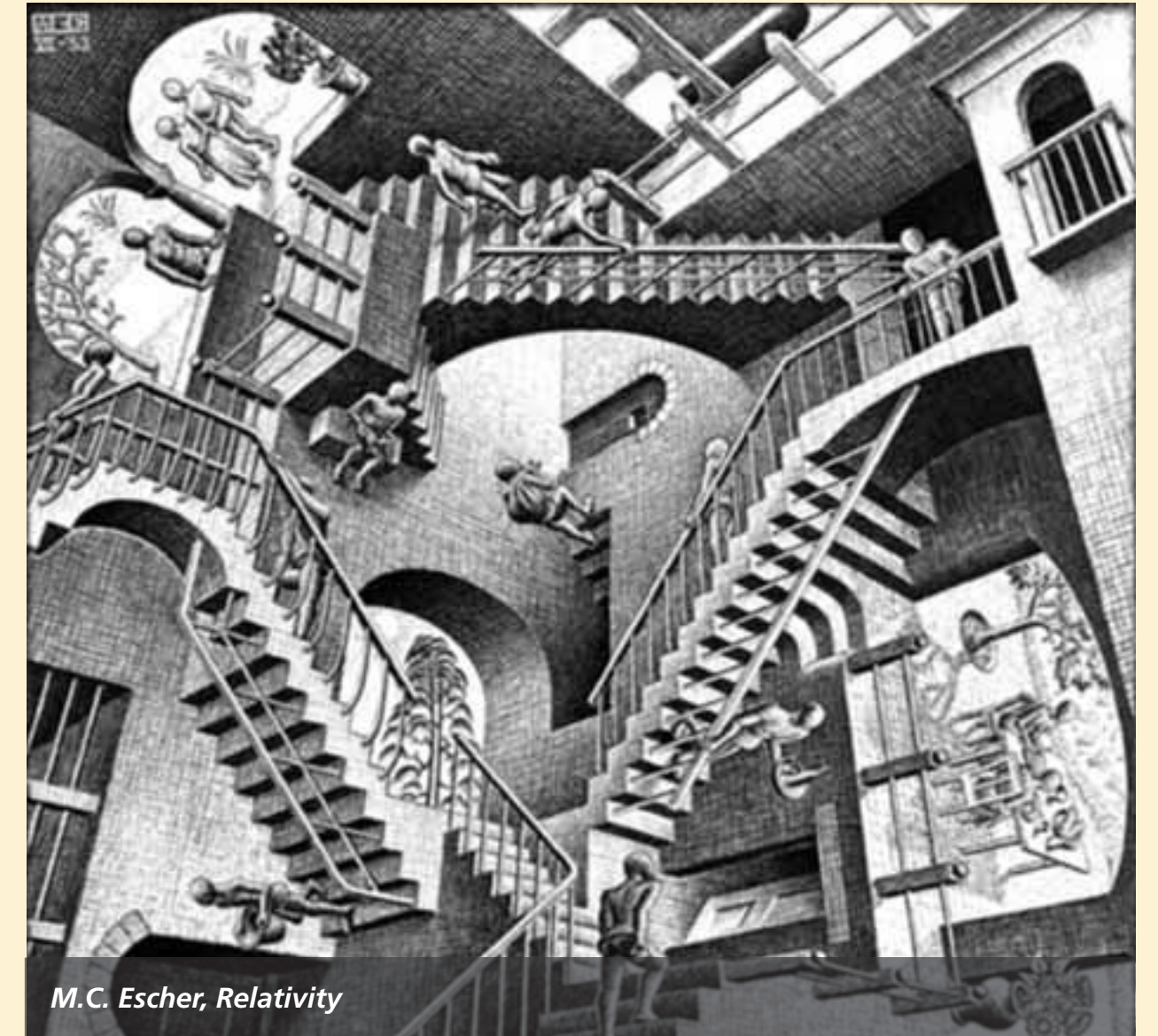
Gwyneth Lewis, in her recent poem, *A Hospital Odyssey*, depicts the hospital as confusing and alien:

“She was enthralled/by the infinite corridors that converged/like a print by Escher.”

“Long escalators ran in spurs,/ moving the healthy as if they were cells/ in a greater body, seeking a cure/for themselves or others.”



Gustave Dore and Blanchard Jerrold, *London: a pilgrimage* (London, 1879)



M. C. Escher, *Relativity*

Joseph’s and Marie’s narratives show how we all use some of the archetypes of storytelling – the common elements of stories that we share – to describe something that is strange, confusing and unfamiliar.

Their illness narratives are very like other stories dealing with places never before encountered. For them, the hospital, like London for Dickens, or the modern medical institution for Gwyneth Lewis, remains a strange place, a place of unease and of perceived surveillance.

Disease as the Monster



Historically, it has been common to write of disease and illness as something monstrous or as an invading force. This characterization can be seen in early modern discussions of gout, in Victorian ideas of epidemic diseases, such as cholera, and in twentieth century understandings of cancer. Here, Charlotte uses some famous fictional monsters to describe kidney disease.

In describing the kidney dialysis ward she was shown around, **Charlotte** wrote:

The room was filled with beds, each inhabited by a very sick looking person who was hooked up to a large, ugly machine. There was a constant low level hum and my strongest visual memory is of blood. Blood being pumped through tubes, out of arms, into machines and back again.

In his novel, *Dracula*, Bram Stoker describes the monstrous Count Dracula as follows:

And then I saw something which filled my very soul with horror. There lay the Count, but looking as if his youth had been half restored. For the white hair and moustache were changed to dark iron-grey. The cheeks were fuller, and the white skin seemed ruby-red underneath. The mouth was redder than ever, for on the lips were gouts of fresh blood, which trickled from the corners of the mouth and ran down over the chin and neck. Even the deep, burning eyes seemed set amongst swollen flesh, for the lids and pouches underneath were bloated. It seemed as if the whole awful creature were simply gorged with blood.

Charlotte continues her account by describing the patients she sees there. They have:

sad yellow faces, out of which stared dull, lifeless eyes.

In *Frankenstein*, Mary Shelley describes the monster in strikingly similar ways:

His yellow skin scarcely covered the work of muscles and arteries beneath; his hair was of a lustrous black, and flowing; his teeth of pearly whiteness; but these luxuriances only formed a more horrid contrast with his watery eyes, that seemed almost of the same colour as the dun-white sockets in which they were set.

What is clear from Charlotte's account is that she does not think of the kidney patients as monsters. Rather, she identifies their illness as something monstrous which has attacked them, just like the monsters of these tales of terror.

Susan Sontag has argued that illness was often talked about through metaphor: that disease was discussed as something else, rather than dealt with head on. She claims that this led only to the avoidance of truthful discussions about disease and its effects – that disease becomes a metaphor for something else.



However, Charlotte's illness narrative, by the very fact that it does use the metaphor of disease as monstrous, manages to imply exactly what it was like trying to come to terms with kidney disease. Perhaps unconsciously, Charlotte also writes in the long tradition of imagining disease as the invading monster.

Questions of *Authority*



would have answered his [the doctor's] questions with a dry humour... But mum was not well, we had been there, saw what had happened, we knew her better than they ever could."

While this might seem like a very modern narrative, there are connections with earlier accounts of encounters with medicine. For example, numerous eighteenth century letters and diaries illustrate how families made choices about treatment and contested medical authority.

Our narratives also reveal how it is not always doctors who are the focus of families' narratives, but often those involved more closely in patient care, with carers dividing up such medical professionals into 'good' and 'bad'.

Historians have charted the growing power of medical practitioners as professionals – either as doctors or nurses, but they are also aware that this was not always a one-sided process: patients often had 'agency'; for example, in asserting their rights to medical care. But what about their families?

Although writers are now familiar with the idea that medical authority can be 'contested', our narratives reveal further ways in which carers and family members can challenge medical authority – either because they have their own 'expert' knowledge as patients or as practitioners or because they believe they know what is best for their relative.

In her story of how her mother was treated following a stroke, **Emily** explains *"I am a nurse, I am supposed to know what to do but it is so different when it's your own"*. From Emily's perspective, medical authority was not transferrable when the tables were turned. Yet, Emily argues for a different form of authority. She goes on to explain, *"Had mum been well enough she*

In **Josephine's** diary about her mother's time in hospital, Josephine regularly points to what she see as neglect and how the nurses *"had been very rude" to her mother, ignoring her or dismissing her claims. In her account, the nurses are "threatening and derisory" and it is the doctors who "are doing their best."*

Although Emily is critical of the nursing care her mother receives in the general hospital, this view changes when her mother is transferred to a smaller community hospital. **Emily** wonders *"Maybe it's a Valleys thing", as she explains how "every member of staff porters, domestics, care assistants, nurses and doctors seem to pick up and respond to our needs."* Emily tells us something about the importance of familiarity and belonging here, and hints at the significance of place in the encounter with medical professionals.

Such narratives suggest that it is both the relationships of power in the encounter with medical authority, and where that encounter takes place – rather than the nature of medical authority – which can produce tensions.



The Healthy *and the Sick*



Numerous writers refer to the idea that medical institutions can be unfamiliar, forbidding places; that patients in them can feel alienated and acutely wrenched from their families. But what of those who care for the sick, the healthy who have to engage with the hospital and the illness as well? In the nineteenth century, for example, strict rules governed the visiting of patients. At the Hospital for Sick Children in London, unless infants were being breastfed, parents could only visit their children for an hour or so a week.

Historians and contemporary writers are less clear about how families and carers respond to these institutions. Work on the Hospital for Sick Children by Andrea Tanner suggests that carers – in this case mothers and fathers – could equally feel disoriented by being in hospitals. Studies of illness narratives regard the voices of the healthy as speaking as though they are on the outside looking in rather than experiencing the illness of their loved one with them.

This impression is brought out in **Marie's** account of *travelling from Llantrisant to the Royal Orthopaedic Hospital in Birmingham for her husband's biopsy. Where we might imagine it is her husband who feels frightened and alone, we hear how he moved beyond his "terror" into "state of reassured optimism"; "settled and relaxed" in his hospital room.* From being strong and organised, Marie has a different response to the hospital. Writing about the family accommodation, **Marie** explains how she *"felt like an imposter" and in various parts of the hospital how "I was inappropriately standing in their space". As someone who is healthy, Marie felt alone in the world of the sick.*

Florence also feels this sense of the separation between the world of the sick and the world of the healthy in writing about going with her mother for a diagnosis. **Florence** very eloquently conjures up the experiences of the waiting room: *"The people left in the waiting room were all silent, serious and keeping themselves to themselves. It wasn't a place where people talk to each other as you didn't know if you were someone awaiting bad news or if they were... Everyone left the waiting room very fast as soon as their loved one came out".* The silence here highlights how impossible it is for the healthy to speak: normal conversation is not possible because the voice of illness has taken over.



However, this is not always the case. Writing about her nan's final days at a community hospital, **Sylvia** explained how she and her family *"stayed all night... talking about memories of our time with nana, laughing and crying."* *Sylvia speaks positively about how "the room was filled with so much love I hope she felt it and it brought her some comfort."* In Sylvia's account the healthy, and their voices, become part of the illness experience. This helps her to "accept and deal with" the illness of her close relative.

These narratives say much about how families can feel isolated just as much as patients. Marie expresses this very clearly when she writes how she was "Displaced, unsettled and invisible". Yet Sylvia's story also reveals how important it can be to break through the barrier between the healthy and the sick: it is a vital way of connecting the carer to the patient, and dispelling the disorientation and alienation of the medical environment.

Narrative *and* Experience



Heath Hospital, Cardiff

Caring for someone with a chronic condition can be a relentless experience. Below, **Edith** describes a visit to the Heath Hospital in Cardiff with her husband Julian.

"I arrived to find the consultant addressing all his questions to Julian – oblivious of me – and oblivious of the fact that Julian's stroke damage means, of course, that he can't remember anything, but he can find something to say in answer to all the questions – just not necessarily the right answer, and the doc diligently wrote it down and I felt, of course, in an awkward situation – if I said anything he would assume I was bossy and interfering – but I knew, as he clearly didn't – that Julian had memory problems – but as a retired teacher he tended to talk with great authority on any given subject – regardless of the fact that he would not remember much about what had happened to him."

At one level, Edith's account is about authority. Her expertise on Julian as an ill person to be cared for is out-ranked by the consultant's expertise on Julian as a

series of medical problems to be solved with science. However, there is something else going on here. Arthur Frank, an expert on illness narratives, argues that the form of someone's story can give us clues as to their state of mind. He would call Edith's story a 'chaos narrative', as shown by the length of the sentence and the way that it is fragmented by dashes. The passage conveys Edith's sense of being constantly buffeted by the demands of her role, unable to finish a thought or action before having to meet the next challenge. There is no resolution to her story - it merely continues as a series of events coming one after another without respite.

We can contrast this with the story told by Edith's daughter **Florence** about supporting her mother through breast cancer. Unlike Edith, whose husband will not get better, Florence's experience of her mother's cancer had a defined end. That allows her the space she needs to look back on the experience and make some kind of sense of it. As Florence explains at the end of her story:

"Looking back I feel incredibly grateful. Things could so easily have been so different. I was in a state of sublime ignorance before mum was diagnosed with cancer. I loved her and valued her and was aware of how much we all rely on her but it had never really occurred to me that she could and would one day not be there [...] The cancer could (God forbid) come back but I hope and pray that it won't and you can only take one day at a time and value the people around you while they are there."



Velindre Cancer Hospital, Cardiff

Writers such as Frank would call this a 'restitution narrative' in which the subject becomes healthy once again. There is also a sense that Florence feels she has learnt something important through this difficult experience.

Yet there is also the spectre of the disease's return here, a sinister entity that attacks and invades the body and which renders normal life abnormal. In this way Florence represents her mother's cancer as a monstrous and malevolent force. Although vanquished for now, it continues to threaten, in both biological terms and as a looming presence over Florence's feelings towards her mother Edith. With this in mind, it is interesting that Florence invokes religion as a defence against a disease which medical science has had only partial success in combating.

Language *and* Control



Emily's mother as a young woman

People caring for sufferers of long-term conditions often make sense of their experiences by adopting specialist medical vocabulary. **Melanie** takes this approach in response to decades-long uncertainty around the diagnosis of her husband's degenerative illness:

"There are a number of genetic conditions which present symptoms like my husband's [...] One of these conditions is Fredericks Ataxia. However, the tests were all negative and no defective or missing gene was identified in my husband. Although the general diagnosis was still genetic but the name of the condition was slightly changed to Spino Cerebellum Ataxia [...] There are around 300 people in South Wales with similar 'ataxia' symptoms and the Heath hospital had began a research into this [...]. It is now thought that condition is auto immune. This means that an anti body is attacking the body and has caused the symptoms. Another symptom of this is Vitiligo, which causes a reduction in pigmentation resulting in white patches on the body. [...] However, the diagnosis is not concrete and may change again in the future."

Louis uses a similar approach when writing about his daughter's condition:

"At the end of this process, Prof. Chalmers concluded that Eleri's condition should be re-diagnosed as Asperger's Syndrome or high functioning Autism, which is on the Autistic Spectrum Disorder (ASD), with

underlying ADHD and Dysphasia. At last, we had a firm diagnosis, but it had taken 24 years of her life to get to this position."

In both accounts the naming of the illness is important. Louis implies that finding the 'true' name of his daughter's condition gives him and his family some power over it. Conversely, Melanie doubts the various diagnoses of her husband's condition and for her the quest to find its real name, and thus gain power over it, goes on.

On the other hand, some carers choose to highlight the individual rather than the condition. Recounting her mother's last illness, **Emily** writes, *'To appreciate my story you have to know my mum, so I am going to tell you a little about her'*. She then goes on to describe her mother's familial life and extensive community activities, and her strength, kindness, sense of humour. Through this the reader gets a real sense of the person before the illness is even mentioned.

Poetry is another way in which carers sometimes try to make sense of difficult and upsetting experiences that have uncertain or unhappy outcomes. **Clara's** poem about her mother's hospitalisation powerfully evokes feelings of despair and anger:

*"Through dirty glass the morning haze reveals
Pillgwenlly slumbering grey towards the sea
Where giant turbines grind like drab pin-wheels
Observed in dreadful solitude by me."*

*Oppressive heat surrounds me as I hear
The hissing of the mattress where you lie
Wide-eyed. You watch me, helpless, full of fear.
I know the 'Trust' will simply let you die."*

In these verses the geographical context which Clara describes is a metaphor for the emotional landscape

that she inhabits. Scholars have suggested that poetry and metaphor are frequently used by patients and carers to make sense of what they are going through, seeing the act of diagnosis translating these unique 'mythological' accounts into a form to which general medical principles can be applied, and in the process transferring control of the illness experience from the patient or carer to the medical professional. Clara's poem can therefore be seen as an effort to retain control over what her mother's illness means, to make it a story of a person rather than a condition.



View of Pillgwenlly from the Royal Gwent Hospital

Simon, himself both a medical professional and a carer for a family member with cancer, again uses poetry to make a related point. As someone who knows both sides of the barriers between doctors and patients, he has particular insights into the relationship between medical language and expert authority. Perhaps his poem, like Clara's, is an effort to re-assert control over his own experience of illness:

*You wonder if doctors use words to confuse,
Words like 'contusion', which just means a 'bruise'.
Why not be open with use of a name,
So patients don't worry not knowing the same."*



The Off Sick *Project*



The **Off Sick Project** considers the role of narrative in understandings of illness both in the past and the present. It incorporates historical and literary research with present-day stories gathered from the communities of South Wales.

Off Sick focuses on the experiences of family members who support someone with a severe illness, and explores how people in these positions turn those experiences into stories. The project is interested in narratives that deal with visits to medical institutions such as hospitals, since it is as a response to institutional medicine that the idea of the illness narrative arose in the first place.

The findings from the project are being showcased through evening seminars, afternoon colloquia, and through a Summer exhibition. The present exhibition is an exclusive trailer for this larger Summer work.

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For more information visit our website by typing in '**Off Sick Glamorgan**' into Google. From there you can join our Facebook and Twitter groups and keep in touch with what we are doing. Alternatively just e-mail Richard on **rmarsden@glam.ac.uk** to join our mailing list.